

Produced by and for people who have autism-spectrum conditions

Asperger *United*

Edition 73 January 2013



Asperger United

Asperger United is a magazine run by and for adults with autism-spectrum conditions (although some parents subscribe on behalf of their under-sixteens). The magazine aims to put people with the condition in touch with each other and to share information so that they can lead more independent lives.

Please note that *AU* receives over 200 letters each quarter so it is not possible to respond to every one, nor for every contribution to be printed. Discussions on editorial choices will not be entered into. *AU* protects the identity of contributors by not printing full names unless the writer asks for his or her full name to be used.

Asperger United is free. To subscribe you, we need your postal address. We ask for a contribution of £6 per year from overseas readers and £10 from professionals and institutions to cover postage costs. Please make cheques payable to the NAS. Organisations requiring multiple copies: no extra fee, please get in touch.

Editor the Goth

Telephone and production support

The National Autistic Society's Publications Department

Asperger United was founded in 1993 by Pamela Yates and Patricia Howlin, in association with the Maudsley Hospital, and Mark Bebbington and Judy Lynch of the National Autistic Society.

This was in response to a recognised dearth of services for people with Asperger syndrome and the potential for self help and networking as a means of support for this group.

The provisions for editor's and sub-editor's post was to develop a publication that was truly the voice of the people it was aimed at. This post also provided the possibility of work experience and responsibility and has benefited those who have held the position. These are Richard Exley, David Wright, Martin Coppola, Ian Reynolds, John Joyce and the current editor, the Goth (who does not wear black).

Pamela Yates provided support and advice to the editors until the publication was handed over to the National Autistic Society in 2000.

The name *Asperger United* was chosen by the group of original readers as the most "appropriate name" for the publication. This was suggested by Anna Kaczynski, formerly Cohen.

Please send all correspondence and subscription requests to:

Asperger United
c/o The National Autistic Society
393 City Road
London EC1V 1NG
Tel: **020 7903 3595**
Fax: 020 7833 9666

Email: asp.utd@nas.org.uk

All we need is your name and address and we will add you to the mailing list — free of charge.

Thank you to Graeme Lawson for producing the *AU* logo.

Please note that the views expressed in *Asperger United* are not necessarily those of the editor, the National Autistic Society or those involved in the publication of the magazine.

Asperger United is available in **large print** on A3 sheets (double the size of this page). If you need large print, please let us know using the postal or email addresses above.

Contributions for the next issue should reach *AU* by **11 February 2013**

Welcome to the first edition of *Asperger United* since the end of the world — well, that's according to some people's interpretation of the Mayan calendar, at least! I trust you are all still there.

This will also be the first issue which gets sent to everyone who wants it, if, as I hope, the database problems have finally been sorted out (except for a little bit of human error, of course).

The database will also keep a record of who wants the e-mail notification of when the new issue is available on line, so thank you to everyone who returned the card or let me know in any other way. Unfortunately, some people tried to use the card to subscribe to the paper

version: to subscribe you to the paper version I need your full postal address, not just a postcode (which refers typically to fifteen houses), and definitely not a complete blank — some people tried to subscribe this way, but whether they forgot to put their e-mail or their postal address, I can have no idea! One person just wrote, "Please could you cancel my subscription to the magazine. Thank you." — I cannot unsubscribe you if I don't know who you are!

On a less technical note, the theme of fear and anxiety proved fertile, so I will be returning to it in future,

the Editor

the anxiety edition — the next issue notice is on page 15

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The blindness and autism connection

by June Bowden

For many years now I have been convinced of the links between blindness and autism in terms of behaviour and psychology, whether lived with separately, or as a dual experience.

Having read many autobiographies of autistic people and knowing what I do from first-hand knowledge of blindness, I am more and more of the opinion that my hunches were correct and that characteristics are common to both groups.

The “island state” experience

An autistic person can see (unless also blind) yet remains trapped or contained within what has been described by parents and autistics as “living behind glass”, through which they can observe the world but not understand what goes on within it. The world is a confusing place in which social cues are misinterpreted and body language, intentions and behaviour of both themselves and others are not understood. Sense data is not prioritised properly and loud noise, changes in routine, textures, smells and clothes can be irritating, provoking high levels of anxiety as can large crowds and gatherings of unknown people. Mannerisms develop in order to compensate or help cope with this confusing world, including hand flapping, spinning, rocking and other forms of stimming such as coin or pebble rolling in the hand, as is head rolling. (These are also all common to the blind except perhaps pebble or coin rolling except in those also autistic). They seem to live in a world within a world, with either delayed speech, unusual prosody or being self-absorbed.

The blind, especially those with no vision like me, live also within themselves in that they remain disconnected from the world. Like the autistic, the blind person’s world is known fragmentally. Only the bit that is being sat on, touched, stood on or lain on forming the complete whole which

is only a fragment of the whole, be it a room, a house or a street. Anxiety is also provoked by changes of routine especially when a child. I hated changes of clothes throughout the day, brought back the first of two meals that had to be prepared for me because my sense of smell was so acute, did not think the key that I dropped into the bath as a child existed once I had let it go and am sometimes confused by social cues, tend to misinterpret meaning if someone sounds serious but is not or doesn’t sound it but is. I head-banged as a child, something also common to the autistic, and like them do not like large gatherings or crowds. Also, like many autistic people, I prefer large chunks of solitude but not to the extent that I become overwhelmed at its absence. Many blind people, as do many autistic people, talk too loudly and some invade personal space, talk incessantly without realising they are boring others or causing the others to stare with embarrassment. Like the autistic, I am certain to ignore someone I know rather than acknowledge them in the street, but this is obviously because I haven’t seen them whereas the autistic may well not think it is important to acknowledge them, thinking that looking at a butterfly or the patterns sunlight makes is of more interest than acknowledging someone. For obvious reasons I cannot make eye contact and the autistic choose or are compelled by their condition not to. As with someone who has Asperger’s syndrome, I have an extremely strong moral code, am irritated by seemingly trivial things such as the mispronunciation of words and have a strong sense of justice. I have described myself as being (in emotional terms) like a bundle of exposed electricity cables that have no insulation.

How do I know I am not autistic?

I have empathy, so much so that I can almost feel the suffering others go through. It’s like a physical pain that I get in my back and I have a

properly developed theory of mind, in that if I am with someone who suddenly says: “I wonder if there are any parcels left for me downstairs?” I know they really want me to leave their flat, as is the case if they say: “Gosh! Look at the time! Is it teatime already?” I turn-take in conversation though I am talkative which may have become more apparent because I live alone and spend long periods of time alone so make up for it when with people. I know if I have physical pain I need to tell someone as they won’t know unless I do but I feel on the edges of society — an outsider who doesn’t march to the same drum as many others. I like and feel at home in the company of autistic people. Our similarities strike me as being greater in number than our differences. I have quirky and original ways of thinking but no savant abilities. I have poor fine-motor skills which make doing up shoelaces or clasps on necklaces almost impossible. As I am encouraged only to talk about one aspect of myself — blindness — to all and sundry, I have possibly become egocentric, like an autistic person with a special interest, so I often say (to those who will not take offence or think I am belittling autism) that I am autistic by default. I would imagine that when blindness and autism occur in one person it may be hard to know which of the two conditions is responsible for which traits, so great is the overlap.

The blind and the autistic respond to music. In the blind, the visual cortex is requisitioned for the processing of musical information and many are very good musicians; sadly I am not among them. I believe music to be a universal language that was probably the forerunner of speech. I relate far better to Labradors than to many people but that may be because they accept me, as do children, with whom I have a natural affinity. I know when I am genuinely liked and not suffered by someone who is feigning interest, empathy or sympathy and the auras of some people provoke strong reactions in me to the point where I know whom it’s best to avoid. As with the autistic, I puzzle over why some people find it so much easier to make friends, especially when also blind but, again, like the autistic, I know I need them. I stood on the edges of the school playground,

fearing getting hurt by rough-and-tumble games, was always the last to be picked for sport, which I hated, was described as a late developer though my early language skills were apparent as were my comedic abilities. Of all the disabilities that I know and all the disabled people whom I have known, it is the autistic with whom I most readily identify and warm to. I see them as being special, uniquely gifted though often troubled, isolated islands like me who are like half-brothers and half-sisters, born of the same blood and cast in the same mould. My overwhelming feeling as I continue to read their autobiographies and books written by clinicians about the condition is: “You could be talking about me.” As I read, with enormous interest, *Born on a blue day* by Daniel Tammet, I am evermore aware that my hunch is correct in that the links between blindness and autism are strong and plentiful. You could be forgiven for thinking that the deaf, who also have a sensory loss, or the deafblind, who have the dual loss of hearing and sight, would be people with whom I feel more akin, and though it is true that I have known both deaf people as neighbours and deafblind people as friends, it is the autistic who, like no others, have provided me with answers about my own thinking, life experiences, feelings and “blind island” state. They hold a special interest and a fascination for me that is becoming rather like the special interest of someone with Asperger’s syndrome in that, if I am not careful, it could border on obsessional. I certainly don’t need much encouragement to talk about it, and when talking to blind friends I hear that many of them too have poor motor skills, poor spatial awareness, high levels of anxiety, but not all are as happy as I am to avoid large crowds, parties, and feel themselves to be outsiders quite as much as I do.

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Interestingly, I also feel that I have theory of mind and empathy — indeed, I often feel overwhelmed by the emotions my empathy causes — though perhaps they were late developing. Does anyone else feel that the characterisation of autists as without empathy is odd, and that most people lack empathy for us? I look forward to your comments, the Editor.

Dear Goth

For many people vision seems to be the predominant sense, what gives them their sense of coherence. For me it is sound; for me sound and music are inseparable. White noise in particular seems to calm me like nothing else does. Hoovers, washing machines, radios, all make glorious sounds. This all conditioned me to always be very open-minded when approaching music.

Every sound is music.

I started writing songs at the age of thirteen. I was already making sounds in various ways (cutting up and editing recordings, etc.) but songs seemed to allow me to be more direct. I've never been very good with conventional communication, and song seemed to give me the self-imposed structures to express myself freely around. I have never been any good at applying myself to anything, except in music. The amount of time I must have spent learning guitar chords and changes astonishes me now. I basically did little else for several years. After school, which was a horrendous experience, I went on a popular music course. The music element was fine. What I did not bank on was how impossible I found the social elements. As with school, I found relating to people and making friends excruciatingly difficult. Although I was generally respected musically, this did not compensate for how lonely I felt. After this course I went on another for a year. The same elements applied, although this time I felt more limited by the approach of the course to music. It was very rule-orientated and in thrall to convention. I also started to get unwelcome criticism about my guitar technique, particularly the unusual chords I played, which rattled my confidence. When I stopped the course it was as if a dam had burst. Songs suddenly appeared in rapid succession. For the next five years songs flowed easily, with writer's block nowhere to be seen. Over this period I wrote hundreds of songs, getting more concise in expression each year.

In 2004 I discovered a songwriter called Jandek. He completely altered my idea of what music could be, and opened up my sense of what was possible. Jandek was to influence me heavily, though I have since been able to assimilate his influence into my music more seamlessly. By now I was starting to tire of popular music, which I had been listening to ever since I heard the Beatles at the age of ten. Jandek gave me a way out. My discovery of twentieth-century classical music in 2006 confirmed the course my musical interests were taking, towards increasing complexity and seriousness of purpose.

The year of my discovery of classical music coincided with a massive nervous breakdown which preoccupied me well into the next year. My songwriting pretty much stopped (I only wrote two songs in 2007) but by interest in modern classical music intensified. As with my teen years, I ploughed my problems into constant studying of music: composers, dates, general music history, etc. At the third attempt, I finally got a diagnosis. By 2008 I was starting to write songs reasonably regularly again. However, although I was writing my best songs to date, I was starting to grow tired of my self-imposed limits. In 2009 I got a piano and started improvising on it in a very instinctive, open-ended way. Finally all the modern classical music I had been listening to was starting to influence my own music. Though structurally discursive by very nature, my improvisations seem to have much in common with certain modern composers in their clarity and seriousness of purpose.

I have recently set up a website of all my recordings, an archive of all my music which has enabled me to look at my musical development with renewed clarity. If you would like to hear my music, my website is

www.iusedtofly.com

Less than half my overall output is currently on the site. More will be added.

Thomas

Pen pals

Pen pal number 138

Hi. My name is Jack, I'm 11 and I am from North Wales.

I enjoy playing Nintendo Wii and DS games and I like Lego.

I love various TV shows on Disney, Nick and Boomerang. I find Harry Hill hilarious.

I have a diagnosis of ASD and go to high school in September.

I love swimming and have all my life saver badges.

Hope to hear back from you soon.

Pen pal number 139

Hello, my name is Joseph. I am 24 and diagnosed with Asperger's on the autistic spectrum. I am a high-functioning member.

I love movies, computer games, reading graphic novels, the internet and researching wolves. I have suffered very badly at school from bullying and last year I tried to take my life with a drug overdose. I would love to talk with anyone out there with an interest in wolves or dogs. My favourite three dogs being the border collie, the husky and the Alsatian. I am living with my parents, though soon I am moving into supported accommodation and hopefully from there I will be having my turn at getting my own flat/house. If there's anyone out there with similar interests feel free to chat through email or send me post.

How to place a pen-pal advert

- > All you need to do is send your advert along with your name and address (and email address if you want) to *Asperger United*. You can use the Royal Mail or email. The next pen-pal number will be given to your advert when it arrives.
- > Please note that *AU* does not print dating adverts, as it is unable to provide suitable support.
- > Those under the age of sixteen must have parental permission before placing a pen-pal advertisement in *Asperger United*.

How to reply to pen pals

- > Please remember to let us know the name and number of the person whom your letter is for. (All pen pals are numbered by the editor, not the person who sends in the advert.)
- > Please remember to put your address on your letter.
- > To contact a pen pal, please send your letter to *Asperger United*, c/o The National Autistic Society, 393 City Road, London, EC1V 1NG, or email asp.utd@nas.org.uk
- > We will pass your letter on to the person you wish to contact. However, we cannot guarantee the person will reply as that is entirely their decision.
- > Please note that all pen-pal letters sent via *Asperger United* are opened before being passed on.

****Important notice — please read****

Asperger United is happy to publish pen-pal advertisements but we must stress that we are not a pen-pal or introduction organisation. We do not match people up and we cannot monitor letters (other than the first letter, that is sent via us) so please be cautious when releasing personal details in your letters. The National Autistic Society / *Asperger United* cannot intervene or be held responsible for any ensuing correspondence between letter-writers.

Pen pal number 140

My name's Richard. I live in the New Forest. I am 35 years old, looking for a pen pal of any age.

Pen pal number 141

Hello, my name is Zoe. I am a young woman waiting for an Asperger's assessment.

I enjoy art and the environment. I would like to share experiences about living with Asperger's with women who are from the Bristol/South Gloucestershire area.

Pen pal number 142

My name is Justin and I am a middle-aged man. I live in South Gloucestershire. I was diagnosed with Asperger syndrome last year, and it came as a big shock to me, but it has helped me to understand myself better. However, the outside world is still a mystery to me. My main interest is German World War Two vehicles, especially tanks and aeroplanes. Another interest I have is mediaeval history, particularly the era of King Edward the Third. I would like to hear from anyone who has similar interests. I would prefer communication via e-mail. I look forward to hearing from you.

Pen pal number 143

My name is Lucas. I am 11, nearly 12, and diagnosed with high-functioning autism. I love to play with Lego and read; my interests are history, mythology, angels, astrology, Wicca and tarot. I like to listen to music, play DS, computer and Xbox games. I am learning to play guitar and my best TV programs are cartoons, Nickelodeon – *House of Anubis*, *Drake and Josh*, etc. The last movie I saw was *Avengers*. I love to go to theme parks as Legoland, Chessington Park and others. I have a pet cat. I would like to make friends with people that share similar interests.

Pen pal number 144

Hi, my name is Alun, I am 42, male and living in South Wales. I was diagnosed with Asperger's syndrome about twelve years ago. I have a great love for all music, but especially reggae, and also computer technology. I would like to hear of anybody with similar interests or even different ones. Age does not matter.

Pen pal number 145

Hi, my name is Chris; I'm a-happy-go-lucky 30-year-old guy living in Birmingham: I was diagnosed with Asperger's syndrome two years back, and that explains a lot of other small problems I've had or am having.

My interests and hobbies include computers, gardening, history, art, books, and good food. A lot of my hobbies do tend to be routine-based and learning stuff in that area. Once I got diagnosed, I found out that comes from having Asperger's — it took me twenty-eight years to find that out, but better late than never! As for me, I'm practical, funny, intelligent, a little quiet and introspective, and I never act fully my age all the time! (I should put my age at 20-25, why act any older? :))

I'm also interested in sharing experiences and problems that Asperger's brings: I don't get to meet anybody with autism, and that would be nice to contact people on the same level. Also, till I got a proper diagnosis two years ago, I had all manner of problems and difficulties, and felt really bad about it as I thought that there was something wrong with me: it'll be ace as well to contact people who have had the same problem.

I'm looking to get in touch with any like-minded people, or anybody that fancies a chat: drop me a line?

Dear Goth,

I am 48 years old and was diagnosed only just over a year ago. Having a very rational mind and accommodating personality has enabled me to express my perspective in a variety of contexts, but unfortunately until diagnosis the tendency has been for me to attribute my perspective to the context in question and thus in effect fail to appropriately address it in terms of my experience outside of the context in which it was expressed (on its own). Since I have become eloquent in expressing a perspective, I intend to do so on behalf of those who experience the same problems, but lack the ability to express themselves in a way that achieves understanding, but I realise I must first address my own issues (sort out the muddle), which is ongoing.

I just read the short piece about the conference on the subject of *Women and girls with ASD*, and my immediate response is that less women are diagnosed probably because our society/culture views the female role as predominantly one of servitude so many live out their lives undetected, complying with the demands made of them by their male counterparts, undoubtedly not without a degree of resentment which itself is attributed to our culture rather than their own disposition, when in actual fact its source lies in the fact they have failed to even identify the true nature of their desires, never mind fulfil them.

The “trap” also reflects the tendency for NTs (neurotypicals) to dismiss autistic experience which, enforced at a young age, can precipitate identity issues since the individual concerned must effectively dismiss his own experience (himself).

I write in desperation as I have learnt that when dealing with those who believe that they understand the “condition” but have only second-hand experience of it, this is used as an excuse to ignore problems and predicaments which would otherwise be given attention. If anyone feels that their identity has become a useful tool for others to deny any need to confirm it, please contact *Asperger United*.

I have been put in a position whereby if I do not feel I can achieve something, even if only on behalf of someone else, I feel acute distress and in true form this is being attributed to my “condition”! (I have never felt that my name “belonged” to me, but use it here in blatant defiance of that sense!) I don’t think (ironically) that in this instance any details such as my age and circumstances are necessary other than that I am a “sufferer”/have the condition!

The best way I can perhaps explain what I am trying to say is by expressing my *huge* sense of identification with the authors of all three letters to you in the October issue of *Asperger United*:

“I am 49 years old and constantly battle with the feeling that my life has been a waste, and have no children.” (a paraphrase of Steve)

“All my adult life I have been prescribed psychiatric medications which not only prevented various problems from being realised at source, with the result that I was only correctly diagnosed a year ago, but also caused other health-related problems, and I also have a dog who is my ‘guiding light!’” (a paraphrase of Andy)

“Despite being over-qualified (MA, ‘Professional Practice’ and Teacher Training certificates, BA (hons), BTec, A and O levels) and unwilling to undergo a process of ‘normalisation’, I cannot find any appropriate work.” (a paraphrase of Damian)

By sharing experience, even if it offers no concrete solution, a situation can sometimes be viewed differently and this can bring benefits which previously seemed unimaginable, transforming what had appeared to be a hopeless trap. Now that I have the correct diagnosis, my problems are seen differently, but the diagnosis is often used as an excuse to ignore what can be seen as “symptoms” rather than legitimate problems.

Yours,

Ann

letters to the Editor

Dear Goth, and readers of *Asperger United*,

it has been twenty years since I was an 18-year-old woman, who was diagnosed with Asperger syndrome at the Maudsley Hospital. Along with my Dad's help, we thought up a name for this magazine, which we suggested to the social skills group that I had been attending, also at the Maudsley Hospital. This is how this magazine got its name, *Asperger United*.

I am pleased to tell you all, I have come a long way since then. I am now happily married to Martin and we have three children: Emily is 6 years old, Sarah is 3 and my son, James, is 1. I am now 38, and my husband recently turned 40. We have just had a magic party to celebrate his fortieth.

For one year I helped to run a social skills group, called Sweet Talk, that taught social skills to young adults with Asperger syndrome, mild autism, dyslexia, and other similar conditions. Now that is sadly no longer running I have been attending Northern Lights, a friendship group for people with AS, who meet at 6.30 on the first Wednesday of every month at the Tally Ho pub in North Finchley. However, I have given this up for the time being as I have gone on a creative writing course on Wednesday evenings.

I also worked for Norwood/Ravenswood, a Jewish charity for disabled people, in the post room for more than ten years, but in the end I gave this up for childcare duties. I am still a stay-at-home mother as childcare is so very expensive. However once my son is at full-time nursery I hope to get a proper job. Although I do realise I will probably need some help in getting back to work, as it is very hard to get and keep a job when you have Asperger syndrome. Does anyone out there have any advice on helping me get a job? Are there any training schemes to help people with AS get back into work? I would love to know about them if there are. However, despite this, I am looking forward to the future.

Yours sincerely,

Mrs Anna Kaczynski, formerly Cohen

Dear Goth,

I am a 54-year-old woman with Asperger syndrome, long-term unemployed, living alone independently with no intimate friends or social life.

This, despite the fact that I have good qualifications and have had very many jobs. Sadly, work never lasted long due to a combination of anxiety, stress caused by travelling, endemic bullying in the workplace, sensory problems, sleeplessness, etc.

I can no longer face the thought of a return to work and feel literally sick at the thought.

I have never been married or in a long-term relationship and have no children.

A shame, since I would have loved these things.

Asperger syndrome is directly implicated in difficulties in the workplace and socialising in general — an inability to read body language and discern verbal duplicity alone see to that.

What “society” sees is an attractive, cheerful woman who owns her own house and “chooses” not to work.

I cannot be alone in being treated with disrespect and disbelief when attempting to explain my unemployment.

The *Communication* magazine does not speak to all parts of the autistic community.

It does not speak to people like me.

“Our voice is your voice”?!

What a relief, then, to find two letters in *Asperger United* who feel similarly neglected by both the autism industry and the NAS.

Sincerely,

Eleni

Autscape and other issues

I really liked and identified with *My first Autscape experience* by the Pea Princess. I have not attended the Autscape conference but I am more interested now that I have read this article.

There are some really interesting books on the Amazon website. I found it very interesting to read about the indigo and crystal children*. I can see patterns in these books and the information that I have about autism.

It is interesting to read about the qualities of these children and adults and how humans might evolve in the future. However, my favourite themes are about how schools and the authorities mistreat these children. The children and adults think they are on the wrong planet because of the alien ways of others. It is useful to read about ways to help indigo people, such as eating healthily and getting exercise. It is also good to get out into nature and avoid loud, aggressive places.

I am looking for somewhere safe and quiet to live. I was able to get funding to find a place but I cannot find anywhere suitable. This is an issue that causes anxiety so it would be a useful subject to explore further in *Asperger United*. I won't even start discussing work. If I could find a suitable place to work then I would be able to get a job.

Linda

**"Indigo child" and "crystal child" are alternative or "new age" concepts. Some professionals argue that they are ADHD and autism, but seen as positive characters rather than syndromes. I am trying to be neutral about the matter, like a good journalist, the Editor.*

What an inspiring piece by Hannah! In addition to the point she raises about the merits of measuring creativity in an artificial environment, I wonder if there is also an issue with the understanding of creativity. I create: I design, paint and draw. Every time I read about creativity from successful creative people, the main point is that creativity is always derivative:

Dear Goth

I'm responding to Damian Milton's article in *Asperger United* edition 72, *Problems in living*.

I was fascinated. I read intently. I could pick up most of the reasoning. My thoughts are similar. Damian commented that quality is perceived before it is understood. I think I agree. I'd like to add my twopenceworth. On the topic of a crumbling society it is necessary that change, and drastic change, is brought about. I like the phrase, "charity starts at home." People can be somewhat cagy when it comes to others. We are as a society fearful and without motivation, by and large, to treat each other well.

So a change is needed. And I think charity starts at home. And I would like to encourage readers to reach out in defiance of aggressive attitudes of idleness that have gripped us.

Let's just think of ourselves, each perhaps with quirks and idiosyncrasies, as capable. And do our very best. Because that is our strength. To carry on. Even when it's tough. And I believe society is in a time of change. And better attitudes could be just around the corner.

Instinctively as a society we know that we need something done now and our lack of involvement with each other needs to be addressed. But it doesn't get any easier by gazing at each other in coffee shops.

It starts with a conversation. So let's make the change that we want to see.

Thomas

you build on things created earlier, changing or combining them to make something new. Yet when I read about creative deficiency in people on the autism spectrum, there is always talk of a lack of "originality". Maybe "neurotypical" people are a bit better at hiding their "inspiration"?

Tom (a piece of art by Tom is on page 15)

a letter with an accompanying article

Dear All

I have discovered that the root cause of many of the problems of people with Asperger syndrome is low self-esteem. Not thinking much of ourselves.

I have written an article to that effect and am now sharing this with you all.

I have decided that I do not want to go on not thinking much of myself. I want to be rid of these hang-ups and live the rest of my life without them.

I am going to think more of myself than I do.

People have said things about me and encouraged me and I have not taken these things on board. I am going to believe what people say about me and I am going to believe in myself.

I am going to need support in all of this as I have been entrenched in these habits for years.

From **Debbie**

Self-esteem is root cause of many of the problems that people with Asperger syndrome have

by **Debbie**

I was sitting in my lounge when I had an insight. Low self-esteem is the root cause of a lot of our problems. People with Asperger syndrome have poor self-worth because they have been marginalised and treated badly because of being different. This has led to us not thinking much of ourselves. I am going to list the problems caused by low self-esteem.

Fear of people we do not know or rather fear of what they will say to us when we express our feelings

We are frightened of what people think of us. This leads us to not communicate confidently and effectively and because people base their perceptions on what they see, they will make responses to how we express ourselves which causes the communication problems.

Not expressing our opinions

We do have opinions but we do not express them because we do not think our opinions are important.

Always asking people what they think

We do this because we think that other people's opinions are better than ours.

Being taken advantage of

We will do anything to help anyone because we care, but also out of an emotional need to feel good about ourselves. Some people will play on that and abuse our kindness and we will not always pick up on that.

Anxiety to please

Because we do not think much of ourselves we think that we need to make a good impression on others in order to feel good about ourselves and so that people will like us.

Not talking about ourselves

We are not very comfortable talking about ourselves because we don't think much about ourselves.

Not taking responsibility for our own behaviours

We don't take responsibility for our own behaviours as we think others will do a better job.

There is a solution to all these problems. We need our loved ones, friends and any professionals that are involved with us to encourage us and tell us that we are worth it and that we should think more of ourselves than we do. You can tell us that you are proud of us for us and pleased with us for us, not for you. Tell us when we have done well when we have achieved something.

You can all help us to break free from these hang-ups. Then we will start to see ourselves in a better way and change things for ourselves.

Dear Editor — the Goth,

I am writing re an article in October edition of *Asperger United: Racing thoughts* by Lois. I found it very interesting as it was just like reading about myself. I have been told by people I have "jumping jack" thoughts: talking about one topic, then on to another within a small space of time. I prefer the "racing thoughts" phrase, personally, and I am very grateful to Lois for this article, as I have not been statemented as having Asperger syndrome. I have done an NAS questionnaire, and it was 90% Asperger syndrome. My adult son has a diagnosis of Asperger syndrome by a specialist in autism-spectrum-related conditions and we are extremely alike, personality-wise. I thoroughly enjoy *Asperger United* and the many topics in it. I have in the past tried to get a statement for myself but my GP just refers it to having depression. I obviously do not agree. I live in a very small town and services for anything such as statements are brushed to one side. I do also thank you for editing *Asperger United*, you do a great job!

I do look forward to my next copy!

Yours gratefully,

Toni

What men with AS want to know about women, dating and relationships

by **Maxine Aston**

ISBN: 978 1 84905 269 6

£15.99 / \$24.95

Jessica Kingsley Publishers

review by the Goth

This is the best book I've come across for explaining what is going on in a typical "mixed" relationship, and, although it's aimed at men who have Asperger's, their partners will also be able to gain some insight, as each short chapter explains a problem from both points of view in order to give understanding. Over forty problems are covered, all taken from Maxine's extensive experience of counselling people and couples. She pulls no punches, including one possible solution to relationship difficulties which other books I've read have ignored or not discussed seriously: you could leave. She considers the pros and cons of this with the same even hand that she considers the other options. Elsewhere, she states plainly when things will be hard, sometimes putting the onus on one partner, sometimes the other, and always justifying why some resolutions can't be shared. I wish more books reached this standard.

This book is available from all good bookshops and through Amazon's charitable scheme at

www.autism.org.uk/amazon

and if you use this address instead of the usual Amazon one, the NAS gets a donation from Amazon.

The mental health issue

by Neil

It is fair to say that just about everyone with AS will be likely to have had contact with the mental health profession at some time. From an early age our parents will have been aware that we were different — and these concerns will probably have been increased as they were shared by teachers and others in the community.

Awareness of AS over the last decade or so has made a tremendous difference in the quality of life of people born since 1980 compared to earlier generations. Prior to then we were seen as mad, bad or “maladjusted”. Without an understanding that AS is a neurological problem, the interventions offered were usually inappropriate as they had been designed from a neurotypical perspective. Despite this, numerous Aspies still struggled gamely with the system and many have come out of it without being too badly damaged. For others, however, the story is very different: their self-esteem and confidence have been shattered and they have found themselves driven to the periphery of society.

Most therapies these days use cognitive behaviour therapy (CBT). Whilst — with significant adaptations — many leading AS authorities use it in their practices, perhaps it is time for an alternative to be considered.

Having looked at the options, in my personal opinion the best option is solution-focused brief therapy (SFBT). Instead of concentrating on past (often traumatic) events — which itself can result in perseveration in people with AS, leading them to repeat the behaviours that they were trying to avoid — SFBT is a forward-looking, positive and individually based process. Importantly, from the provider’s perspective, it does what it says on the box: it is a brief, rather than a drawn-out, process.

Traditional therapies require that the therapist takes control. With SFBT, it’s the client who takes

the lead. The key to SFBT is the understanding that everyone already has the strengths, coping skills and other mechanisms from which can be developed solutions to new problems. Therefore, SFBT concentrates on exceptions to problems (ie., times when the problems aren’t happening or are not as troublesome). This helps both participants to notice and identify things that already work well for the client. Again unlike other therapies, SFBT starts from a belief that a client’s aspirations are of paramount importance and therefore, by helping them to identify both what they want to achieve in their lives and the existing resources that can help them obtain those goals, they can achieve their targets.

Unlike traditional methods, SFBT starts with non-problem talk. The SFBT therapist is looking to see what the client’s strengths and resources are and by talking about these rather than the “failures” that brought them together, so the client is already experiencing improved self-esteem. The client will be asked about his goals for the end of therapy: what will be the differences he will experience, and who else will notice them? Small changes to behaviour will be identified, including specific examples, and the success of achieving these will be used as building blocks for further progress.

Many people with AS feel that therapists — who are almost invariably neurotypical — do not understand them. With SFBT, the therapists must always check their understanding of what the client is saying: if nothing more, it shows that at least they are listening!

SFBT uses scales from zero to ten to help determine how people are feeling and achieving. This allows clients to monitor their own progress and notice when there may be problems about to occur and also when things are improving. The more detail a client can put into their description

an article (continued), a notice, art and a letter

of how they want things to be, the more likely they are to be able to achieve their goals.

SFBT isn't new or some wacky "right on" treatment. It has been around some twenty-five years and is well established in the education system, particularly in deprived areas where usual methods of discipline have little effect. Instead, SFBT helps these individuals discover their

own self-respect and self-worth, and attain their revised goals in life.

For more information read: *A self-determined future with Asperger's syndrome* by Veronica Bliss and Genevieve Edmonds (Jessica Kingsley, ISBN: 978 1 84310 513 8, £14.95). Vicky Bliss' website is

www.missinglinksupportservice.co.uk

If sufficient material is sent in, and in contrast to this issue, the theme for April will be **pleasure**. (If little is sent in, how about **insomnia** or **work**? Vote with your contributions: the more letters and e-mails sent in from different people, the more likely that that subject will be the theme). Writing on any subject is still welcome, as are ideas for new themes, fillers (for putting in small spaces like this) and artwork. Remember, if you want to see different content in *AU*, the best way to change it is to send something in!



by Tom

Dear Goth,

my name is Gill, I am 54 and diagnosed with AS in May, 2012. I have my whole life suffered from fear, anxiety, panic and insomnia, never knowing why until diagnosis. My diagnosis had to be private as the NHS didn't have sufficient knowledge to know. My husband has recently become my carer as I have become agoraphobic and can't go out alone. He says my worst problem is fear.

I am pleased you are planning to cover this subject: I would think it is a common problem for lots of AS sufferers. I take diazepam for anxiety, and Zopiclone for insomnia. I have a 32-year-old daughter, a 25-year-old son and three grandchildren. I have all sorts of fears and anxieties about each of them. I have not got a solution to the fear, anxiety and insomnia that accompany AS, but it is comforting and helpful to know that you are willing to address these subjects, as it stops someone like myself feeling so alone and isolated. I also lost many jobs

through fear and anxiety, including my last one. I am unable to work now due to the agoraphobia. I belong to a social skills group which helps me to not feel so alone and frustrated and desperate at times that I get so misunderstood by neurotypical people. This group and your magazine both help me to not feel so isolated with my condition. I want to thank you and I look forward to fear being covered in your next magazine.

Yours sincerely,

Gill

This and the many other similar letters received show why so much of what is published in AU is, not to beat around the bush, depressing: many readers, themselves depressed, find it uplifting to know that they are not alone in how they feel and in how other people treat them. I know that a minority of readers need more positive letters and articles to be published, and I'm sorry that so much of what is published makes those readers sad. I really wish I could please everybody all the time, and I hope the positive content this issue is helpful, the Editor.



No scream by Thomas

Call for papers

The theme is *Cure or curiosity: What drives autism research?* This is a call for papers for *Autonomy*, the critical journal of interdisciplinary autism studies, published through the Open Journal Systems by the Autreach Press.

We are an open-access peer-reviewed journal, with the aim of encouraging discourse between the different academic disciplines engaged in autism research, with the focus on being autistic-led. We therefore particularly welcome and encourage papers from autistic scholars who have not been published before. We invite submissions, academic papers, comment, and reviews (including reviews of all media and conferences).

The submissions process is online but not exclusively so: we will accept papers by email, provided they are in a format that can be read and edited. Alternative modes of submission will

also be considered if this is an access issue, please contact the principal editor for further details.

We do not set a house citation style, but do require citation and referencing.

Authors retain copyright but grant the journal a creative commons attribution 3 licence on any material submitted.

Further details can be found on

www.autreach.info

For any further queries please email the Principal Editor at

autonomy@larry-arnold.net

or send letters via *Asperger United*.

Laurence Arnold PGCert (SpEd) FRSA
Principal Editor

NAS Christmas card competition 2013

The competition is open to adults on the autism spectrum. Under-eighteens can also enter a design in a separate children's category of the competition, which is sponsored by BIC Kids.

NAS president Jane Asher will judge the competition, which closes on Sunday, 10 February, 2013. Winners will also be given fifty cards of their design.

Here are some points to remember:

- Your design should have a Christmas theme and be at least 210mm by 210mm (but it does not have to be square)
- Avoid using shiny colours and objects such as gold, silver and coloured foils in collage work as these are difficult to reproduce in print
- Please write your name, address and age on the reverse with a suggested title
- Do not fold your design
- We cannot return your entries.

Details are also available at

www.autism.org.uk/christmascard-comp

Send your design either by post to:

Christmas card design competition
The National Autistic Society
393 City Road
London
EC1V 1NG

My other condition

by Tee Randall

I'm an adult physically
But my social age is that of a young child
I have toys in my flat
I cry when I'm ill
And I feel unloved when shouted at

I like being told stories
I like being sung to
And I soak up affection

I respond to situations like a child would
And my coping strategies are that of a six-year-old
Yet I'm treated like an adult

This is hard for me because I have a condition
It's called delayed social development disorder

I am sensitive
Can be upset very easily
And require a warm, loving and caring response from adults

For what you see is what you get
I'm a child trapped in an adult's body

© Tee Randall 2011

Tee's book, *A life not lived: through the eyes of an autistic poet* is available from www.lulu.com for £5

Alternatively, you can send your design and details by email. The resolution of your design must be 300 dpi (dots per inch) or more. Please send it to

xmascards@nas.org.uk

Good luck!

Martina

Mental health problems: inevitable or avoidable?

by Elkie

I have often wondered whether mental health problems are an inevitable by-product of Asperger's or whether they are caused by the environment we struggle to live in and would therefore be avoidable.

When I was first admitted to a psychiatric hospital, the diagnosis said "severe OCD and depression with psychotic episodes". What had started off as routines giving order to my life had slowly turned into obsessions, forcing me to do what I didn't want. And the world I used to withdraw to for comfort had more and more cut me off from reality and taken on a life of its own.

I could never pinpoint an onset of mental health problems, as it was more of a gliding scale or even two sides of one coin. As I said, routines are very important to me to keep order and to make things more predictable, but the downside is that I have to stick to them even if they no longer fulfil a purpose. Then they become obsessions that eat up my energy and my time.

The same could be said about the comfort of merging with a sensory world which shuts out the bewildering demands of human interactions, yet it can so easily lead to feelings of alienation and profound loneliness.

There seems to be a very fine line between Asperger syndrome and mental health problems, and, interestingly, the areas of the brain affected by both appear to be the same. The medication and various forms of therapy I was offered during the past years have certainly helped me enormously to function as I do today, yet none of them would ever claim to get rid of my "disability" as it is part of who I am.

So can people with Asperger syndrome avoid mental health problems or not? Research shows that the majority of people with AS suffer from mental health problems even before they reach adulthood. The reasons stated for this are usually loneliness, bullying and general difficulties to understand and fit into society. However, if we had the chance to grow up in an Asperger-friendly society where everybody experiences the world as we do, would we be able to escape those dark, confusing and frightening states of mind or would they still catch up with us?

Perhaps one day research will shed some light on these questions. I would certainly be interested to hear from anyone with AS who has enjoyed mental health all their life.



The rules of *Asperger United*

(contact information for AU is on page 2 and again on page 20)

- 1) *Asperger United* is funded by the NAS and readers' donations, and is independent of the NAS. Although it is called "*Asperger United*" it aims to be for the whole of the (reading) autism spectrum. That is, the concerns and joys of any subscriber on the spectrum can be printed, not just Asperger's.
- 2) *Asperger United* is free and is quarterly, published in January, April, July and October. If you do not receive a copy when you expect to, please contact AU.
- 3) Pieces that appear in *Asperger United* are credited using the author's first name only, unless the author requests something different. This is done to protect your privacy.
- 4) *Asperger United* administers the copyright of everything that appears and it does this on behalf of the authors.
- 5) *Asperger United* does not use your contact details for anything other than administering AU. Your details are not passed on to NAS Marketing, NAS Fundraising or any other organisation without your written permission. Please consider getting involved with the NAS campaigns and events.
- 6) If you move house, please inform *Asperger United* and include your old address as well as your new address.
- 7) Even if you've paid for the Royal Mail forwarding service (or another forwarding service if you live outside Great Britain and Northern Ireland), you still need to inform *Asperger United* that you have moved address.
- 8) If you phone and leave a message on the machine, please speak slowly and clearly and spell uncommon words, as the line isn't very clear. Please give any phone number you leave twice for the same reason. Remember to give your postal address so that we can find your record.
- 9) You do not have to be a member of the NAS to subscribe to *Asperger United*.
- 10) The current edition of *Asperger United* is available at **www.autism.org.uk/aspergerunited** You need to scroll down to the middle of the page, where there is a link to the PDF.
- 11) You can sign up for an email notifying you whenever a new edition of *Asperger United* is posted on the webpage above. Email **asp.utd@nas.org.uk** asking for the notification by email and please include your full name, postcode and let us know whether you want the paper edition too.
- 12) If you want to unsubscribe from the paper version, inform *Asperger United* and include your postal address. Or to unsubscribe from the email notification, include your email address.
- 13) If you want to resubscribe (or subscribe for the first time) inform *Asperger United* and include your postal address (for the paper version) or email address (for the email notification).
- 14) Book reviews are the most popular thing in *Asperger United*, please consider submitting one. They can be about any book, not just books about autism. Also, they do not have to be short (the Goth keeps most of his reviews short to leave more space for other writers). If you do not want your review to appear in the NAS section of the Amazon website, please make this clear.
- 15) Although each issue is themed, submissions on any subject are welcome. Only some of the letters and articles in each issue will follow the theme. All submissions may be edited, especially for privacy, libel, and for fitting the space available.

Jack Haslam, printmaker

My love of animals has been a major part of my life. I have been drawing and taking photographs of animals since I was four years old. Most of my inspiration has come from my many visits to London Zoo and Whipsnade.

I have been told that I have a “flavour” of Asperger’s syndrome, so I have always had problems relating to human beings — I find them to be unreliable and unpredictable. Animals have helped me manage my feelings of isolation. They have an attraction for me as they help me make a bridge between myself and others. I love the detail of different animals: the gorilla’s cheeks; the anteater’s claws — their eyes are almost human. Over the years, I have had many obsessions with different animals, including sharks and chimps, but of all the different kinds of animals, for me the anteater is king.

I decided that conventional art school was not the route I wished to take, as I like to work alone most of the time. After leaving school, I attended City and Islington College to learn life skills, but I was also encouraged to work on my art. In recent

years I have been learning new techniques such as etching, drypoint and collographs (all forms of printmaking) at City Lit and the Mary Ward Centre. I think my drawings have humour, but they can also look a bit desperate. However, I like to put the animals up on a pedestal, and make them almost majestic.

Over the years I have had periods where my mental health has made it difficult for me to draw, but generally it makes me feel happy. I am very proud to have this exhibition, as showing my drawings and sharing my love of animals helps to communicate with other people, and find a common ground for conversation.

I have previously exhibited work at the Shape Open 2012, Bite printmakers at the Mall Galleries, London, and the MOMA Wales.

I would like to thank Monica, my support worker, as I would not have been able to learn etching without her.

www.outsidein.org.uk/Jack-Haslam

Asperger United, c/o The National Autistic Society, 393 City Road, London EC1V 1NG.

Telephone: **020 7903 3595**

Fax: 020 7833 9666

Email: **asp.utd@nas.org.uk**

Website: **www.autism.org.uk/aspergerunited**



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